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Public health indicators for cerebral palsy: A European collaborative study of the Surveillance of Cerebral Palsy in Europe network

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Abstract

Background: Public health indicators (PHIs) play an increasingly important role in health policy decision-making. Although cerebral palsy (CP) is the commonest physical disability in children, its impact at population level has not been systematically measured so far.

Objectives: We aimed to propose six PHIs for CP designed to annually document the extent of CP and effectiveness of perinatal organisation, the burden of this condition, access to health services and preventive health strategies in the post-neonatal period and to report on the latest updated estimations using population-based data routinely collected by European CP registries.

Methods: The study included children with CP born between 2002 and 2011. Harmonised data (number of cases, functional profile, imaging) were extracted from the Surveillance of Cerebral Palsy in Europe (SCPE) database. Eligibility criteria for analyses were applied separately for each indicator by selecting registries, birth years and CP cases. Current estimates were based on the last 3 birth years, while trends were reported over a 10-year period. All analyses were descriptive. Sensitivity analyses were carried out to examine the stability of the results using various thresholds of percentages of missing values.

Results: Analyses were performed on a total of 8621 children with CP from 12 to 17 SCPE registries. A decreasing prevalence of pre/perinatal CP overall, as well as in preterm and full-term-born children, was observed. The burden of the condition was strongly dependent on CP subtype and the presence of associated impairments. Access to brain imaging ranged from 80% to 100% depending on registries. The overall prevalence of post-neonatally acquired CP was approximately 0.8 per 10,000 live births over the study period.

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Conclusions: Population-based CP registries can provide data that are relevant for generating key outcomes of interest at the population level, thus potentially contributing to improving public health policies for children with disabilities.

KEYWORDS

cerebral palsy, children, health indicators, population-based registries

1 | BACKGROUND

The growing interest in evidence-based decision-making to advocate for change and improve health at the population level has led to the development of public health indicators (PHIs), which are increasingly being used to inform the planning of public health strategies and enable action through community programmes.^{1,2} There is no conclusive consensus on their definition in the literature. According to Flowers et al., a PHI is a “summary and synthesised measure that indicates how well a system might be performing.”³ The European Commission has defined a PHI as a “quantitative or qualitative measure of how close we are to achieving a set goal (policy outcome).”⁴ Whichever definition is chosen, emphasis is put on the need to periodically measure the health system performance using existing data sources.^{3,5,6} The study of Khoshnood et al. highlighted the value of PHIs in providing clear summaries for policymakers and emphasised the pertinence of using accurate data from registries.⁷ Such indicators are not only relevant for diseases that affect a large part of the population. Initiatives have been taken in the field of rare diseases to define a conceptual framework and identify the main requirements for the definition of PHIs. It has been suggested that a combination of public health and research issues might be relevant.⁸ Thus, in the case of rare conditions, health indicators could serve to raise awareness about the diseases, document the impact of interventions or public policies, allocate appropriate resources, and also to improve the understanding of the conditions or determine research priorities.

Cerebral palsy (CP) is a relatively uncommon condition, although it is the leading cause of early-onset physical disability.⁹ It occurs in about 1.6 in 1000 live births (LB) in high-income countries.¹⁰ In addition to mobility issues, children with CP may experience a wide range of lifelong difficulties (such as cognitive impairment, epilepsy, communication difficulties, visual or hearing impairment, progressive musculoskeletal deformities, pain), all of which require high-level care.⁹ Given that CP is very disabling for some people, that the disability is lifelong, and that life expectancy is not notably reduced at least for those with the mildest impairment,¹¹ the impact in terms of disability-adjusted life years makes CP a more significant condition from a public health perspective than its rarity might suggest.

In Europe, the Surveillance of Cerebral Palsy in Europe (SCPE) network of population-based CP registries routinely collects harmonised information on children with CP from birth year 1976.¹²⁻¹⁴ As, to the best of our knowledge, no PHIs have been developed for CP to date, our intent was to extend the use of the SCPE database beyond the scope of epidemiological research and to provide

Synopsis

Study question

Can we use data from population-based registries to gain information on the impact of cerebral palsy at population level?

What's already known

Harmonised data obtained from collaboration between registries are relevant to describe periodically the evolution of public health indicators for cerebral palsy. Areas are identified where improvements in the care and prevention of cerebral palsy are needed.

What this study adds

The extent of the decline in the prevalence of cerebral palsy in all risk groups, the burden associated with neurological subtypes and the various impairments associated with motor difficulties, the gap between practice and recommendations for access to brain imaging, the number and evolution of the subgroups with potentially preventable causes are key outputs for improving policy and practice.

policymakers with relevant evidence-based information, by designing indicators which address complementary facets of the condition at the individual and population levels, and which are potential targets for action to improve the lives of people with CP.

The aim of this study was to define a set of simple, relevant and understandable health indicators for CP and to report on the latest results using European population-based data routinely collected for children born between 2002 and 2011.

2 | METHODS

2.1 | Cohort selection

Our study was based on European population-based CP registries participating in the SCPE network (<https://eu-rd-platform.jrc.ec.europa.eu/scpe>). Registries cover either a region (with a



surveillance area of at least 3000 LB per year) or their whole country. They share the same definition of CP, that is, a group of permanent but not unchanging disorders of movement and/or posture and of motor function which are due to a non-progressive interference, lesion or abnormality of the developing brain.¹⁵ This definition specifically excludes progressive disorders of motor function, defined as loss of previously acquired skills in the first 5 years of life. Children with hypotonia as the sole clinical feature and children with isolated spinal neural tube defects are excluded. The diagnosis is made on the basis of clinical description, independently of pathology or aetiology. Children with CP were eligible for this study if they were born between 2002 and 2011.

2.2 | Outcomes

We used registry pseudonymised data on children with CP (numbers of cases, functional description, neuroimaging) combined with population data using the census or any official population data source (LB the same year in the same catchment area).

The following data were used: gestational age categorised as <37 weeks (preterm) and ≥ 37 weeks (term-born children); CP subtype (unilateral or bilateral spastic, dyskinetic, ataxic forms);¹⁵ walking ability reported in 3 categories using the Gross Motor Function Classification System (GMFCS),¹⁶ GMFCS level I or II (independent walker), GMFCS level III (walker with aids), GMFCS level IV or V (wheelchair). We considered the following associated impairments: severe intellectual impairment (defined as an intellectual quotient (IQ) <50 or clinical equivalent); active epilepsy (defined as the need for active treatment for epilepsy); severe visual impairment (blindness or no useful vision). Data on brain imaging (at least one brain imaging test during or after the neonatal period, yes/no and magnetic resonance imaging (MRI), yes/no) were also extracted from the records.

Six descriptive indicators covering four areas were created reflecting the extent of CP and effectiveness of perinatal organisation (1st area, two indicators), the burden of the condition (2nd area, two indicators), access to health resources (3rd area, one indicator) and prevention during the post-neonatal period (4th area, one indicator). The first area used the birth prevalence of CP, defined as the risk of developing CP before the age of 5 years in relation to a population born in the same year in a given area. It is a measure of long-term consequences of perinatal complications and is relevant for understanding the effectiveness of the organisation of maternal and neonatal care, policies and practices.¹⁷ It usefully complements the neonatal mortality rates available at country level. First, we used the total population as a denominator (indicator 1). Second, we presented the prevalence separately in preterm and full-term infants because the underlying mechanisms leading to CP during intrauterine life and in the neonatal period differ between these groups (indicator 2). The second area identified was the burden of the condition.¹⁸ Children with CP may have multiple

health care needs in the long term. A detailed description of disability patterns could help to inform health care needs, to investigate the adequacy of resources and services (such as rehabilitation services) and, on a wider scale, to estimate the economic burden of CP. The two chosen indicators were the severity of the gross motor function impairment according to the predominant motor function pattern that defines the CP subtype (indicator 3) and the presence of severe associated impairments according to walking ability (indicator 4). In children with CP, neuroimaging, preferably by MRI, is widely and consensually recommended to understand the pathogenesis, to explain the severity of the functional profile and to help establish a prognosis.¹⁹ Imaging of the brain (indicator 5) was thus selected as an indicator of access to services (third area), with the proportion of children with CP who had had at least one neuroimaging investigation (ultrasound, computerised tomography (CT) scans and/or MRI) and the proportion who had had at least one MRI scan during the neonatal period or during infancy. The five indicators defined above should be measured in children who are affected by pre/perinatal CP. Causal pathways that ultimately lead to CP are very different when the brain insult occurs post-neonatally, after the 28th day of life and before 2 years and are often easily identified. In such situations, some causes (such as infections or head injuries) are potential targets for primary prevention opportunities (including immunisation against infectious diseases, car safety, pool fencing).^{20,21} Consequently, the prevalence of post-neonatally acquired CP (indicator 6) was chosen to reflect the effectiveness of preventive health strategies in the post-neonatal period (fourth area).

2.3 | Statistical analysis

Criteria for selecting registries and instructions for deriving the indicators are detailed in [Table 1](#). Eligibility criteria were applied at the level of registries, of birth years and of each studied criterion, for the estimation of each PHI. When estimating birth prevalence trends (indicators 1, 2 and 6), the population for analysis was restricted to registries that collect such data (number of cases and number of LB) on a regular basis, that is, at least 5 years of data collection over the study period. For this reason, the number of registries included in the analyses potentially differs for each birth year across the period.

All indicators were calculated at SCPE level, except for indicator 5 for which the results were detailed by registry. Prevalences were estimated using weighted average of yearly registry point prevalences (number of children with CP born to mothers residing in the area at the time of child's birth divided by LB in the same year and in that specified area) and reported per 1000 LB and per 10,000 LB for pre/perinatal CP and post-neonatally acquired CP, respectively. Evolution of prevalence over time was presented over a 10-year period (birth years 2002 to 2011) using a 3-year unweighted moving average to smooth out short-term fluctuations. Other indicators



TABLE 1 Public health indicators for cerebral palsy, Surveillance of Cerebral Palsy in Europe. Definition, characteristics, calculations

Area covered	Definition of the indicator	Criteria for selecting registries/data	Reference period area of reference
1st area: extent of CP and effectiveness of perinatal organisation	Indicator 1 Trend in the prevalence of pre/perinatal CP per 1000 live births	Registries with at least 5 birth years available over the study period, with both cerebral palsy cases (numerator) and live births (denominator) available	Birth years 2002–2011 Mean SCPE trend (3-year moving average smoothed data)
	Indicator 2 Trend in the prevalence of pre/perinatal CP per 1000 live births according to preterm (<37 weeks gestational age) and term-born children (≥37 weeks)	Registries with at least 5 birth years available over the study period, with both number of CP by gestational age (numerator) and number of live births by gestational age (denominator) available for each registry and each year of birth, no more than 20% of missing gestational age	Birth years 2002–2011 Mean SCPE trend (3-year moving average smoothed data)
2 area: burden of condition	Indicator 3 Distribution of gross motor function impairment (GMFCS level I or II; GMFCS level III; GMFCS level IV or V) by cerebral palsy subtype (unilateral spastic, bilateral spastic, dyskinetic, ataxic)	No more than 30% missing data (GMFCS or cerebral palsy subtype) by registry during the entire study period	Birth years 2009–2011 SCPE level
	Indicator 4 Presence of severe associated impairments <ul style="list-style-type: none"> • Severe intellectual impairment (IQ <50), • Active epilepsy (need for an active treatment for epilepsy), • Severe visual impairment (blindness or no useful vision) by walking ability (GMFCS level I or II; level III; level IV or V)	No more than 30% missing data (GMFCS or IQ/epilepsy/severe visual impairment) by registry during the entire study period	Birth years 2009–2011 SCPE level
3rd area: access to resources	Indicator 5 Proportion of children with CP who had had at least one brain neuroimaging test (ultrasound, CT and/or MRI scans) and proportion of children who had had at least one MRI	No more than 30% missing data (brain imaging, MRI) by registry during the entire study period	Birth years 2009–2011 By registry Note: no comparison with SCPE average, expected value 100%
4th area: Preventive health strategies in the post-neonatal period	Indicator 6 Post-neonatally acquired CP per 10,000 live births	Registries with at least 5 birth years available over the study period, with both post-neonatally acquired CP and live births available	Birth years 2002–2011 Mean SCPE trend (3-year moving average smoothed data)

Abbreviations: CP, cerebral palsy; SCPE, Surveillance of Cerebral Palsy in Europe; IQ, intellectual quotient; GMFCS, Gross Motor Function Classification System; CT, computerised tomography; MRI, magnetic resonance imaging.

describing the current CP situation were estimated by selecting CP cases born in the last 3 birth years (2009–2011) available at SCPE level (severity, indicators 3 and 4) and by registry (brain imaging, indicator 5). Three birth years were used to mitigate potential annual variations.

2.3.1 | Missing data

For the prevalence by gestational age group (indicator 2), the registry birth year for year *i* was excluded if more than 20% of missing data on gestational age among the CP cases was observed in the registry for year *i* or if LB by gestational age were missing for year *i*. For each indicator related to the burden of the condition (indicators 3 and 4), all the registry's cases were excluded if more than 30%

missing data were observed during the study period for at least one variable of analysis.

2.3.2 | Sensitivity analyses

Sensitivity analyses were performed to examine the stability of the indicators calculated at SCPE level under various specifications of eligibility criteria. For indicators 1 and 6, this was done by selecting various lengths of data availability over the study period (from 5 birth years to 10) to include data for trend analyses and by comparing the annual estimates to those obtained with the length reference (5 years). For indicators 2, 3 and 4, various percentages of missing values (from 0% to 100%, the latest threshold being equivalent to “no constraint on missing values”) were considered.



TABLE 2 Public health indicators for cerebral palsy, Surveillance of Cerebral Palsy in Europe. Data availability

Indicator's number	Definition of indicator	Registries/cases excluded	Number of children and number of registries selected for analysis
1	Trend in the prevalence of pre/perinatal CP per 1000 live births	Less than 5 birth years available: 3 registries (111 cases)	8621 children with CP 17 registries
2	Trend in the prevalence of pre/perinatal CP per 1000 live births according to preterm (<37 weeks gestational age) and term-born children (≥37 weeks)	Less than 5 birth years available: 3 registries (111 cases) No denominator by gestational age over the whole period: 4 registries (808 cases) or for some years: 3 registries, 8 birth years (144 cases) % missing gestational age >20%: 4 registries, 8 birth years (402 cases) Cases with missing gestational age: 452 Gestational age outlier: 1 case	6817 children with CP 3178 preterm and 3639 term-born children 12 registries
3	Distribution of gross motor function impairment (GMFCS level I or II; GMFCS level III; GMFCS level IV or V) by CP subtype (unilateral spastic, bilateral spastic, dyskinetic, ataxic)	% missing GMFCS > 30%: no registries % missing CP subtype >30%: no registries Cases with missing GMFCS: 54 Cases with unknown CP subtype: 69	2364 children with CP 16 registries
4	Presence of severe associated impairments <ul style="list-style-type: none"> • Severe intellectual impairment (IQ <50), • Active epilepsy (need for an active treatment for epilepsy), • Severe visual impairment (blindness or no useful vision) by walking ability (GMFCS category: level I or III; level II; level IV or V) 	% missing GMFCS > 30%: no registries % missing severe intellectual impairment >30%: 2 registries % missing active epilepsy >30%: 2 registries % missing severe visual impairment >30%: 3 registries Cases with missing GMFCS: 56 Cases with missing severe intellectual impairment: 146 Cases with missing active epilepsy: 61 Cases with missing severe visual impairment: 117	1630 children with CP for severe intellectual impairment analysis 1715 children with CP for active epilepsy analysis 1659 children with CP for severe visual impairment analysis 13 registries
5	Proportion of children with CP who have had at least one brain neuroimaging test (ultrasound, CT and/or MRI scans) Proportion of children with CP who had had at least one MRI	% missing brain imaging >30%: No registry Cases with missing imaging: 127	2360 children with CP 16 registries
6	Trend in the prevalence of post-neonatal acquired CP per 10,000 live births	Less than 5 birth years available: 3 registries (10 cases)	358 children with CP 16 registries

Abbreviations: CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; IQ, intellectual quotient; MRI, magnetic resonance imaging; CT, computerised tomography.

2.4 | Ethics approval

This study was based exclusively on pseudonymised registry data compiled at European level in the SCPE database. It did not require any contact with the registered persons. Therefore, ethical review and approval were not required.

3 | RESULTS

A total of 9969 children with CP registered in the SCPE database were born between 2002 and 2011. The proportion of missing data and population available for analysis are detailed in Table 2.

Figure 1 shows the 10-year average SCPE trend in the prevalences of pre/perinatal CP overall and according to preterm and term-born groups (indicators 1 and 2). The overall average prevalence decreased from 1.9 to 1.6 per 1000 LB during the study period. Sensitivity analyses found no evidence of significant differences in the annual SCPE average estimates according to sample selection using varying lengths of the study period (Appendix S1). A similar decreasing trend was observed over the study period both in preterm children and in term-born children (from 12.3 to 9.7 and from 1.0 to 0.8 per 1000 LB, respectively), although the trend was less marked in the latter group. No differences in SCPE averages were found according to the percentage of missing gestational age either in the preterm group (Appendix S1) or the term-born (Appendix S1) group, although higher variations were found when the accepted percentage of missing gestational age was lowered.

Figure 2A (indicator 3) shows the distribution of GMFCS by CP subtypes. In unilateral spastic forms, 1% of children used a wheelchair whereas this proportion was 40% in bilateral spastic and 63% in dyskinetic forms. No registry had more than 10% missing data on CP subtype or GMFCS (Appendix S1). The presence of severe associated impairments increased with increasing gross motor function impairment (Figure 2B, indicator 4). Among children unable to walk (GMFCS level IV-V), 75% had an associated severe intellectual

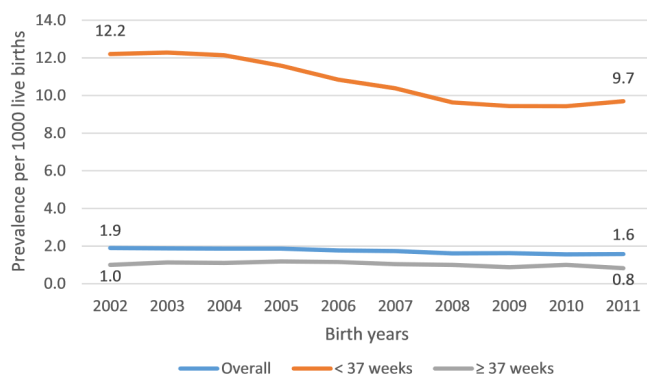


FIGURE 1 Trend in the birth prevalence of CP per 1000 live births, overall ($N = 8621$ pre/perinatal CP cases, 17 registries, 2002–2011) and by gestational age groups ($N = 6817$ pre/perinatal CP; preterm: <37 weeks $N = 3178$; term-born: ≥ 37 weeks, $N = 3639$; 12 registries, 2002–2011).

impairment, 58% active epilepsy and 25% severe visual impairment. The findings did not change when considering other cut-offs of missing data on impairments (Appendix S1), except when no missing value was accepted, which was verified in one registry only.

The proportion of children with CP who had had at least one brain imaging test (ultrasound, CT scan and/or MRI) and the proportion who had had at least one MRI scan are presented by registry in Table 3 (indicator 5). Access to brain imaging ranged from 80% to 100% (7 of the 16 registries). From 65% to 100% of children with CP underwent MRI brain study.

The prevalence of post-neonatally acquired CP (indicator 6) was at around 0.8 per 10,000 LB over the study period (Figure 3). Sensitivity analyses found no evidence of significant differences in the annual SCPE average estimates according to sample selection (Appendix S1).

4 | COMMENT

4.1 | Principal findings

Based on data accrued from 12 to 17 Surveillance of Cerebral Palsy in Europe registries with 8621 CP cases, this study shows that the overall average prevalence of CP was 15% lower at the end of the study period compared to 10 years earlier. This downward trend was also observed in children born preterm and at term. Walking ability was patterned by CP subtype. And the presence of severe associated impairments increased with increasing gross motor function impairment. Access to brain MRI varied from 65% to 100%, depending on region. Prevalence of post-neonatally acquired CP was approximately 0.8 per 10,000 LB over the study period. The results showed little change when the thresholds for inclusion of registries and data in calculating PHIs were modified.

4.2 | Strengths of the study

The indicators chosen were the result of a lengthy process involving successive workshops and discussions at working group and SCPE levels to reach consensus, although unlike the Delphi method this process was not structured in formal rounds. However, professionals and experts were encouraged to revise their options in the light of their colleagues' opinions. The PHIs that were defined reflect a consensual understanding of the key outcomes of interest at the population level. The multi-professional and multidisciplinary nature of the SCPE network helped to avoid major methodological weaknesses and ensured that the PHIs were widely agreed. Because they are based on data that are routinely collected in CP registries around the world, PHIs for CP developed by the SCPE can be used internationally. Current estimates (using the 3 most recent birth years) and time trends (over a 10-year period) need to be updated annually (by adding the latest birth cohort after the new data submitted have been validated and removing the oldest birth cohort) to ensure that the descriptive information provided is up-to-date. The results should



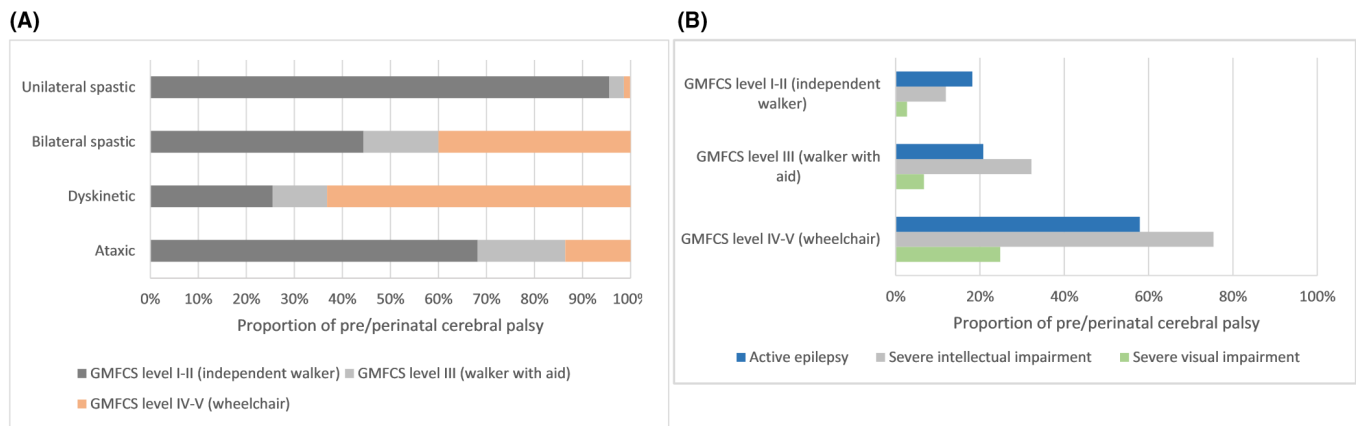


FIGURE 2 (A) Distribution of gross motor function abilities by CP subtype (indicator 3), 2364 children with pre/perinatal CP born 2009–2011, 16 registries. (B) Presence of severe associated impairments by walking ability (indicator 4): severe intellectual impairment $N = 1630$, active epilepsy $N = 1715$, severe visual impairment $N = 1659$ children with pre/perinatal CP born 2009–2011, 13 registries.

TABLE 3 Proportion of children with CP having access to any brain imaging and to brain MRI, $N = 2360$ children with CP born 2009–2011, 16 registries

Registry	Any brain imaging performed (%)	MRI performed (%)
Iceland	100	100
Isère and Savoie, France	100	93.1
Sunderland, United Kingdom	100	88.9
South-West Hungary	100	78.4
Croatia	99.5	82.8
Eastern Ireland	99.4	94.8
Attica region, Greece	99.1	80.2
Belgium	99.0	94.8
Haute-Garonne, France	97.8	71.9
Western Sweden	96.4	87.8
Portugal	95.0	81.8
Northern Ireland	93.5	93.5
Slovenia	93.0	65.1
Norway	89.2	87.5
Canton St Gallen, Switzerland	82.6	82.6
Malta	80.0	80.0

be interpreted in the context of the population surveyed and disseminated through appropriate means to help improve their use and influence decision-making. PHIs for CP have been drafted for publication on the SCPE website (https://eu-rd-platform.jrc.ec.europa.eu/scpe/public-health-indicators_en) with commentaries on their definition and interpretation and additional technical notes on relevant points.

4.3 | Limitations of the data

The proposed indicators are purely descriptive, in line with the PHIs definition of providing simple and regularly updated information.

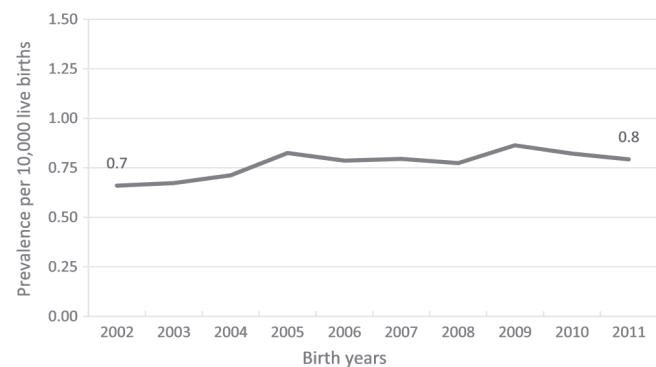


FIGURE 3 Trend in the birth prevalence of post-neonatally acquired CP per 10,000 live births (indicator 6), $N = 358$ cases, 16 registries, 2002–2011.

The calculations included as many registries as possible, which led to a varying number over the study period, introducing potential heterogeneity. Given registries differ in size, average estimates of prevalences or distributions do not necessarily accurately reflect the estimates for each registry. Variations between registries may be due to differences in characteristics of the population surveyed, scope of the registry, local priorities for the care of children with CP and organisation of care, or timing of implementation of new practices.²² Therefore, any comparison between registries should not be interpreted without data on this contextual information, which is not currently available in the SCPE database. This contributes to explain why most indicators are reported at SCPE level. Furthermore, it cannot be excluded that, despite SCPE reporting procedures that aim to limit the number of lost to follow-up, there were structural differences between the registries in terms of completeness of registration, plus external constraints, such as parental refusal, which is however generally low but may vary between registries.

The existence of missing data is also a limitation, although it is inherent to the accuracy of data in medical records. However, the percentages of missing data for the key variables of gestational age,



CP subtype, and GMSFCS were low (<10%). Conversely, associated impairments that may be difficult to collect for some registries are more often missing than the above key variables. Nevertheless, the results of sensitivity analyses were reassuring. They did not show significant differences from the pragmatic decisions we made regarding the accepted missing data threshold (20% or 30%).

Finally, live births, which correspond to the population at risk for developing CP, are not the optimal denominator to reflect the extent of the condition in the community. It would have been preferable to consider children residing in the region at the age of ascertainment regardless of their place of birth. However, to date, the data required (children with CP and population data) to calculate period prevalence are not readily available or accessible to every registry contributing to the SCPE. In particular, registries should have access to data on children with CP who moved into the surveillance area between birth and age 5 and verify that all children with CP born in the area and registered before age 5 are still alive and living in the area at age 5.

4.4 | Interpretation

There were a number of challenges to overcome in designing PHIs for CP. The main challenge related to the objectives of collaboration between registries for a rather rare condition. The SCPE was established to bring together population-based data on CP. Beyond issues of harmonisation across Europe, there was a need to provide reliable estimates of trends in prevalence over time and to have sufficient statistical power to study causes, subtypes, subgroups or health service questions, which was not conceivable when considering individual registries. Although comparisons between registries, which is the primary idea when examining the performance of healthcare systems, are a desired outcome, they have proved to be challenging, primarily because of the limited data available per year and per registry. An example of this is the choice of post-neonatally acquired CP. In our view, this is a very relevant PHI for assessing preventive health strategies during the post-neonatal period, as a number of causes are preventable. However, it cannot be used for comparisons between regions because of its rarity (less than 1 in 10,000 children). Only large networks can provide reliable trends, as has been done in the past in Europe^{20,23} and Australia.²¹ Patients' access to brain imaging is the only indicator for which we have chosen to present the results by registry. Although the finding of a similar proportion of children who undergo brain imaging may reflect different practices (availability of MRI, type of imaging performed), the aim is not to make comparisons between registries, but for all registries to reach a proportion of 100%. This would mean that all children with CP underwent neuroimaging during infancy, as recommended worldwide.^{19,24,25}

Although this work is not an exhaustive review of the subject, the simplicity of some indicators does not always sufficiently reflect the complexity of the disease. For example, the risk of CP is much higher in children born preterm than in children born at term, which

justified the separate calculation of prevalences. However, this risk clearly increases with decreasing gestational age at birth. Therefore, it would be interesting to further split the preterm group and to examine the changes in birth prevalence in moderately, very, or extremely preterm babies. Secondly, complementary indicators could use period prevalence, considering children residing in the region. For example, the period prevalence of severe functional profiles (non-walkers with or without severe intellectual impairment) might be relevant to complete information for services planning purposes.

5 | CONCLUSIONS

We show that population-based registries can provide useful data for generating health indicators. The sharing of PHIs for CP could already help to improve public health policies towards people with disabilities in Europe and to increase public awareness of this complex condition.

AUTHOR CONTRIBUTIONS

CA and MD conceptualised the study and wrote the first manuscript. VE, AP and ML performed the statistical analyses. CA supervised the study and wrote the final manuscript. All authors contributed to the interpretation of the results, reviewed and approved the final version of the manuscript.

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CONFLICT OF INTEREST

The authors declared that they have no conflict of interests.



DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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